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Biodigital Publics: Personal Genomes as Digital Media Artefacts

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ABSTRACT *The recent proliferation of personal genomics and direct-to-consumer (DTC) genomics has attracted much attention and publicity. Concern around these developments has mainly focused on issues of biomedical regulation and hinged on questions of how people understand genomic information as biomedical and what meaning they make of it. However, this publicity amplifies genome sequences which are also made as internet texts and, as such, they generate new reading publics. The practices around the generation, circulation and reading of genome scans do not just raise questions about biomedical regulation, they also provide the focus for an exploration of how contemporary public participation in genomics works. These issues around the public features of DTC genomic testing can be pursued through a close examination of the modes of one of the best known providers—23andMe. In fact, genome sequences circulate as digital artefacts and, hence, people are addressed by them. They are read as texts, annotated and written about in browsers, blogs and wikis. This activity also yields content for media coverage which addresses an indefinite public in line with Michael Warner's conceptualisation of publics. Digital genomic texts promise empowerment, personalisation and community, but this promise may obscure the compliance and proscription associated with these forms. The kinds of interaction here can be compared to those analysed by Andrew Barry. Direct-to-consumer genetics companies are part of a network providing an infrastructure for genomic reading publics and this network can be mapped and examined to demonstrate the ways in which this formation both exacerbates inequalities and offers possibilities for participation in biodigital culture.*

KEY WORDS: Direct-to-consumer genome (DTC) testing personal genomics, 23andMe, publics, biomedica, biodigital

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Introduction

New biotech start-ups, established healthcare providers and genomic researchers made direct-to-consumer (DTC) genome tests available in the early twenty-first century. They advertised a revolution in healthcare through promises of democratic access to genomic information. This innovation in the biotechnological industries gave rise to concern within biomedicine, health regulatory agencies (primarily in the USA and UK), academic disciplines linked to biotechnology and the mass media. Media coverage, including celebrity endorsement, of these new services has been an integral part of their emergence, and the internet has been crucial to this phenomenon.

In the context of these developments, which bring biomedicine and digital media together with revolutionary promise, it is important to ask: what are the political features of DTC genomics? This can be pursued by giving attention to a subset of other questions, including: who engages with these tests, what are the processes involved in DTC genomics and what are its features?

I begin by considering the main recent controversies generated in the wake of the emergence of DTC genomics, and then propose some analytical resources for tackling the broader political questions raised above, before offering an analysis of the general features of the public dimensions of DTC genomic practices through a case study of *23andMe*.

DTC Genomics: Recent Political Controversies

DTC genomics has overwhelmingly been understood as a biomedical regulation issue. For example, in the late 1990s the UK biomedical regulatory agencies anticipated that consumer tests would soon become available and that new kinds of regulation would be required as these services would disaggregate testing from clinical services and the established counselling framework (Human Genetics Commission, 2003, 2006). The subsequent debates which emerged around testing, and the resulting legislation, have been almost entirely focused on medical models of disease association testing within healthcare budgets (Human Genetics Commission, 2003, 2006; House of Lords, 2009).

Nevertheless, DTC genomic testing is not only a biomedical matter and the emphasis on this dimension has obscured other political aspects of these services. There are similarities between DTC genome publics and other biomedical or health-consumer publics such as those which have emerged around HIV (Epstein, 1996) and cancer (Gibbon, 2007). However, although a biomedical framing certainly characterises the debate around the emergence of genome scanning, this does not exhaust its political features. Indeed, once genome scans circulate as texts in digital culture they invite readers. This makes them readerly texts—that is they are artefacts directed towards inviting readings and readers. Rather than biomedical practices as such (DTC genomics largely has a promissory

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relationship to biomedicine) these texts operate at the intersection of digital bio-sociality, consumption and knowledge production.

Despite this broader range of operations, concern about biomedical issues has also predominated in academic assessments of DTC genomic services and this focus extends to related arts, humanities and social science enquiries. The key academic questions around DTC services which have emerged so far pertain to how consumers understand genomic information and what they do with it *as prospective patients*. Thus, other scholars have tracked the number of DTC genomic companies and the different regulatory questions which have emerged in their wake (Prainsack *et al.*, 2008; Salari, 2009; Curnutte and Testa, 2012). Others have looked at DTC as part of a new trend in open and collaborative science and Lee and Crawley (2009) argue for the importance of using social network analysis in this context. Although this literature has been primarily concerned with the figure of the patient, DTC companies promise to empower people through genomic consumption. Recent work also examines the construction of this genome consumer (Levina, 2012; Harris *et al.*, 2012). Levina (2012) suggests that the genome consumer is part of a more general digital networked subjectivity and Harris *et al.* (2012) argue that DTC creates a social bond obscuring the clinical labour of participants. My argument here speaks to this turn towards the politics of consuming genomes.

However, I want to consider the kind of public that is being made in terms of both the political promise to change the power relations of biomedicine and the foreclosure of such politics in DTC genomics. In tackling questions concerning genome publics it is important to think about the ways that genome scans are not only *biomedical* media but are also being circulated as *readerly artefacts of digital culture*. My framing of scans in this way focuses on the circulation of genome sequences and scans as digital texts.

Cheap and fast genotyping and sequencing technologies enabled both established players and new companies to offer DTC genome test services, which range from scans to full sequencing. Genome scans can be understood as texts that offer a set of meanings about genomics to the reader. They are made up of two elements. The first is referred to as 'raw data' and this is the analysis of chromosomes including the DNA bases, genes and markers for variations (SNPs). Raw data vary amongst the service companies because they use different methods to extract such data. The second element is a report generated through an analysis of this primary material. These also vary across companies because they are based on different data and also because they are organised in different ways. The raw data and the reports can be updated as ideas about both of these elements change in response to developments in genomic science.

Analytical Framework

Two analytical frameworks are helpful in tackling these questions: one is Michael Warner's (2002) work on the construction of political publics through the reflexive

circulation of texts and the other is Andrew Barry’s (2001) study of interactivity, including its ideological features. Taken together, synthesised and extended, these two frameworks may be helpful in untangling some of the contradictions at the interface of genomics and social media. As the following analysis charts, DTC
 140 genomics involves the construction of a public through the circulation of texts and this has been overlooked by the almost exclusive preoccupation with its bio-medical applications.

Much of the following discussion is informed by Michael Warner’s claim that a
 145 public exists ‘by virtue of being addressed’ (Warner, 2002, p. 50). Warner argues that the circulation of texts to an indefinite audience which reads and responds, often by writing into the text, is constitutive of a political public. Such an audience can be said to be indefinite because it can’t be measured. An address extends in unpredictable ways as texts circulate without definite end. This indefinite circula-
 150 tion, already a feature of print media, is exacerbated by the networked conditions of digital flows. The circulation of texts and their reach to readers creates what Warner refers to as a ‘scene of address’. A public can be understood through his work as one which is characterised by self-assembly, visibility to itself and political voice. DTC texts promise political agency, whilst failing to deliver on those
 155 conditions, but, as I elaborate below, the address of genomic texts is political and solicits a public.

Warner notes that one difficulty in understanding contemporary readerly
 160 publics is that the texts by which they are addressed are not always easily recognised as texts (Warner, 2002, p. 51). However, his insights allow genome scans—as a composite of raw data and report—to be understood as circulating texts implicated with a genome reading public composed of both individual consumers and an indefinite audience. The circulation of genome scan data and reports occurs through the generation and exchange of digital texts creating a biodigital scene
 165 of address. These scans provide interpretive frames for genomic information linked to physical and behavioural characteristics deriving from the broader field of genetics. Warner’s perspectives suggest that a genome reading public may have political agency because such publics are, in many ways, self-organising, visible to themselves and others, and able to address specific issues. As will be
 170 argued below, a genome reading audience exhibits some of the characteristics Warner associates with such publics.

Like other publics Warner considers, a genome reading public ‘is as much
 175 notional as empirical. It is also partial since there could be an infinite number of publics within the social totality’ (Warner, 2002, p. 51). There are several indicators that genomic reading has become a matter of public concern, one element of which is the legislative attention it has been given. Another indicator of this public-ness is the range of media attention DTC genome scanning has elicited and the consequent expansion of its possible public. These aspects of the formation of a DTC genome scanning public are both explored below.
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The argument set out here is that the construction of a genome reading public through DTC genomic websites instantiates significant constraints which are set through the conditions of engagement with social media. I identify these constraints and the features of this engagement in the case study of one particular DTC genomic testing service below by drawing on Andrew Barry's (2001) analysis of interactivity, including his identification of its ideological aspects. Social media revolve around the promise of interactivity. Barry (2001) argues that the promise of interactivity conceals a coercive mechanism, which is the compulsion to interact. The circulation of digitised genomic information operates through promises of personalisation, interactivity and empowerment associated with both genomics and digital culture. However, the promise of personal empowerment, entailed in the personalisation of genomic information, obscures the political cost of this participatory culture and the loss of collectivity which may result.

Genomes on the Internet

Genome reading publics are primarily web-based and the circulation of scans is in a digital infrastructure. Mapping this scene involves considering media coverage of genome scan and sequence readers, genome scan companies, the direct-to-consumer providers and the research projects which feature in this field.

Displaying some of the components in this public scene (see Figure 1) illustrates that this circulation results from activity at the intersections between biotechnology and digital culture. *23andMe* exemplifies this and these intersections are apparent in its mode of operation. Backed by *Google*, as an initiative bringing together biomedical research and consumer genomics, *23andMe* provides online genome scans to its customers and promotes interactive and personalised genome reading as a form of political empowerment. In doing so it conflates consumption and agency in a way which characterises the politics of digital culture more generally. It sells the promise of empowerment and this results in a commodification of the audience, but at the same time, the generation of digital genomic texts brings a public into being through an address. As the following analysis illustrates, it is this scene of address that makes DTC genomics an important example of the formation of publics in the contemporary political landscape.

Publicity and the Promotional Publics of Personal Genomics

The public dimensions of genomics involve intersecting forms of biosociality and consumption. People are involved in genome scanning through the consumption of digital media which draws media audiences into the construction of knowledge about biology. In addition to involving a form of media consumption, DTC genomics includes the activities of taking tests and of reading meaning into genomic information. These activities are made into spectacles through media coverage. This happens in TV and press coverage of celebrity genome scanning, for

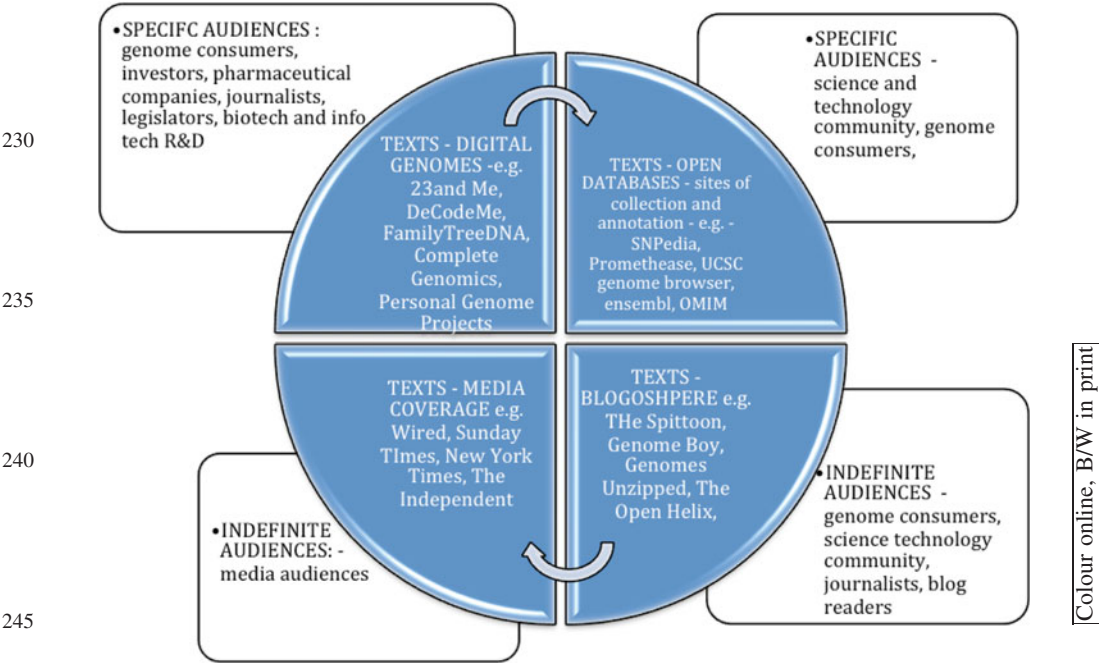


Figure 1. Chart of the scene of address of digital genomic texts including texts and audiences.

example. The attention of an indefinite audience is elicited through media coverage of genome reading. Hence, media coverage of genome scanning exacerbates the public-ness of the biodigital idiom and this is a key dimension of DTC genomic services.

In fact, the media audiences for DTC genomics are much more extensive than the direct consumers involved in DTC scanning. In the last few years the emergence of big research projects and new DTC companies has generated high-profile press releases, media controversies and celebrity interviews. Documentary and life-style programming, news programmes, magazine and newspaper articles, and popular science writing focused on DTC genomic developments have followed. In addition to these more conventional forms of media, the technology and science-orientated blogosphere has also attended to personal genomics. All of these media forms and forums have registered interest in and publicised DTC genome scanning and sequencing. This publicity has been characterised by its preoccupation with celebrities, and with media and technological elites. For example, USA celebrity genomic scientist Francis Collins has made numerous media appearances in which he has discussed his experiences with genome scanning, and a number of similar accounts by celebrity-scientists or media figures (e.g. James Watson, Steven Pinker, Thomas Goetz) have circulated in a variety of media. Moreover, genome scanning is often dramatised in media

representations through the foregrounding of issues of racial identity and death and dying. These features are evident in programme titles, such as *The Face of Britain* (UK television Channel 4), *Faces of America* (US television PBS), *The Killer in Me* (UK television ITV), and *DIY Genetic Test: I Want to Know the Worst* (UK press, Ironside, 2007).

The employment of the internet as a multi-dimensional core component of DTC genomic scanning provision is also crucial. The internet is the vehicle for publicity, but it also functions as the point of payment, of customer services, and as the interface for the resulting genomic information. The internet enables the circulation of genome sequences as digital media and attaches the data and reports produced to a range of other forms. It facilitates forum and blog discussions about the experience of testing, comparisons of the practices of different companies, assessments of the state of the field, and evaluations of diverse aspects of the information provided through DTC genomic scanning. Genome scanning generates a public because, in Michael Warner's (2002) terms, it addresses a constituent audience but it is also open to indefinite view, networked as digital media at inception. It enables forms of debate about gene chips, the annotation of individual genomes through genome wikis, such as *SNPedia*, and open-source analysis software, such as *Promeathese*. In negotiating these forms, people compare raw data from different companies and invest in knowledge construction about these practices.

These participatory activities are forms of media production and demonstrate a synchronicity between the practices involved in genomics and those of digital culture. In this context genome scanning is at once an activity of individual privatised consumption and also a collective public activity. In the circulation of genomic digital texts both individual and collective subjects are addressed at once. The individual genome consumer is addressed as part of a collective of digital media participants and genomic research subjects. Genome scans don't only reside inside privatised browsers, they also circulate through digital media and discussion about them circulates further, across multiple media forms. This entails a public of intersecting media audiences who are addressed by genomics and who produce more media. This also offers genomics to indefinite others who may be agonistic or indifferent to genomics (Figure 2).

The specific consumer publics of DTC genomic testing constitute niche markets about which information can be sold to interested parties. This makes genome scanning similar to other web-based social networking forms in which user-generated content, designated as public, becomes privatised as propriety corporate content through the platform which facilitates the content. The pattern of current digital media is for the content of social networking to be sold to advertisers, through the brokerage of information architecture (such as *Facebook* and *Google*), which aggregates consumer content. Hence, the formation of reading publics involves the creation of aggregate genomic information as well as consumer profiles and content. Genome scanning practices diverge from those of

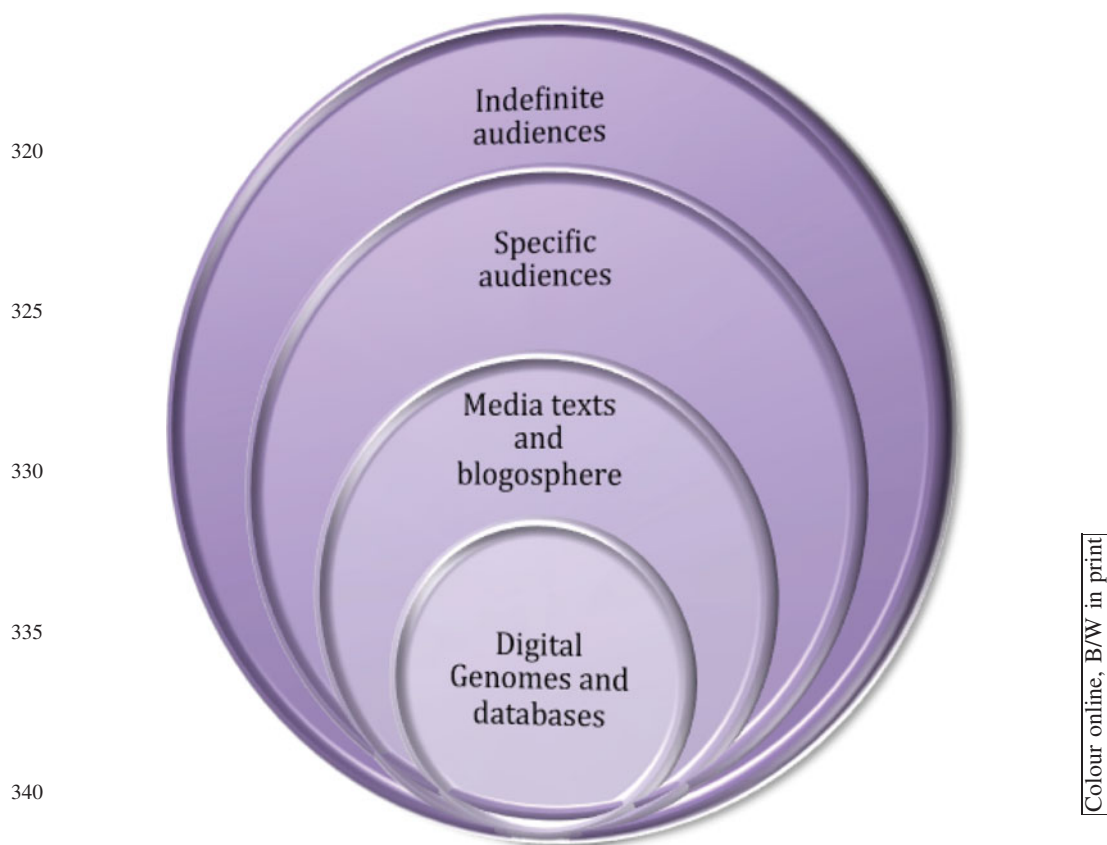


Figure 2. Chart of the scene of address of digital genomic texts.

Facebook and *Google* in their current forms because the goods enclosed in the former’s processes are genetic samples, genomic information and cohorts for bio-medical research. These are solicited from consumers of DTC genomic scanning in the name of interactivity. Making genomics public though digital media enables an enclosure of public goods and the production of commodities.

These patterns of consumption and new ways of accumulating biocapital are crucial, but this is not the whole story of DTC services. As Stefan Helmreich (2008) indicates in his review of the literature on biocapital, the focus on capital is narrow. Capital is not the only product of the consumption practices of a bioeconomy. Consumer practices are also about the making of publics and this entails forms of politics, involving the making of selves and structures, substances and imaginaries. Publics are created at this site through the media textuality of online genome scanning and through the self-representations of genome scanning in blog posts and commentaries, as well as through the broader coverage of these activities in print and TV media. This is a public with political possibility

Colour online, B/W in print

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because the space to reinterpret or challenge the power relations of genomics is opened through the indefinite circulation of digital genomic texts.

Consumer Genomics: *23andMe*

As noted above, *23andMe* is the web-based DTC company at the centre of this analysis. Named after the 23 human chromosomes, this firm is not a drug development company. It operates as a consumer interface, selling tests to consumers, thereby apparently positioning itself as downstream. However, it also operates as a biotechnological research facility (which would be regarded as upstream). Its customers are simultaneously consumers, producers and research subjects and this category convergence generates the tension at the heart of much discussion about *23andMe* and DTC genomic sequencing services. As an assemblage this DTC company realises a mixing of publics and ‘upstream’ technoscience in new forms of encounter not registered in established models of public engagement with science. This convergence generates a consumer public through both the invitation to participate in the production of genomic digital media and in the ensuing address of this media as it is circulated to these participants and to an indefinite audience.

23andMe draws on the market strategies of *Web 2.0* to generate publicity, to ensure customer co-creation of content, and to incorporate recursive content with attention focused on personal genomes in a networked context. Such strategies also include efforts to attract customers through media coverage, recommendations and networking. *23andMe* offers consumers genomic analysis of saliva samples. The DNA sample required in the *23andMe* kit involves the collection of 2.5 milligrams of saliva. Successful saliva collection and analysis leads to the provision of personal genotypic information through a browser interface. The company provides raw genome scans with information about 118 disease and trait associations, and ancestry analysis, linked to individual genotypic information. It also provides extensive interpretation of this information and invites consumers to expand this interpretation. This is a user-generated or co-created content model of media production where users provide tissue samples to generate the data and contribute to the media content through commentary and annotation. Like *Facebook*’s uploaded content, this model depends on the audience’s willingness to recursively contribute to the address of *23andMe* by adding to the digital text (Figure 3).

23andMe asks people to ‘Join the Research Revolution’ and invokes both personal and collective responsibility, e.g. ‘genetics just got personal’; ‘join us’. *23andMe* evokes a sense of an elite, but public, project of politics and knowledge production. Maintaining these features and attracting a critical mass of users are key strategies for *23andMe*. The appeal to a public imaginary is partly dependent on getting enough people on board and sustaining public debate about the phenomena. The company saw periods of rapid growth at the end of 2008 and

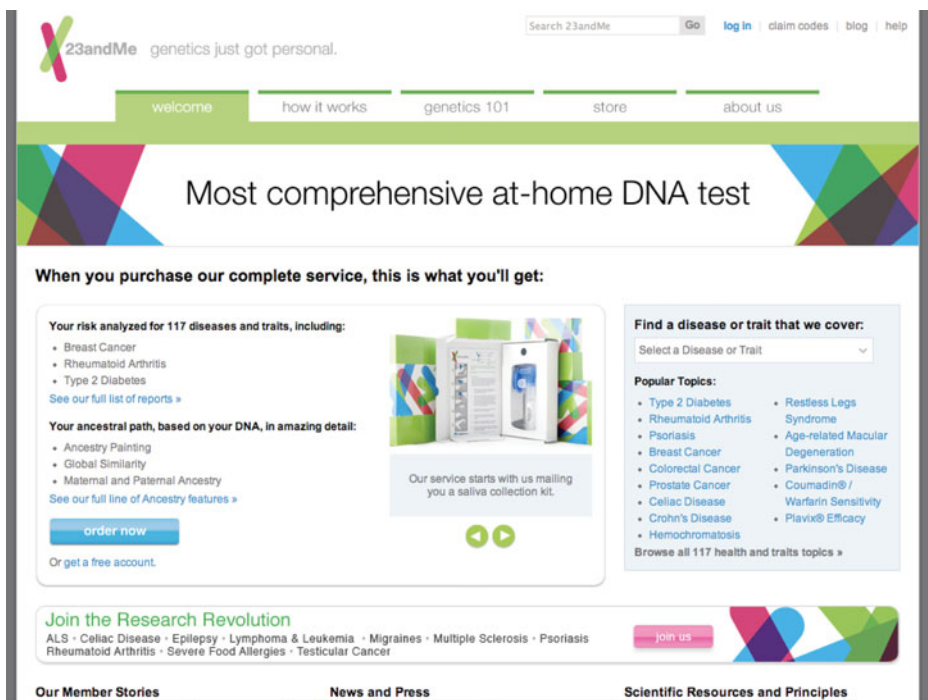


Figure 3. 23andMe: Genetics just got personal.

in early 2010, following high levels of media exposure. Initial recruitment occurred through celebrity events and endorsement with journalists, media workers, biotech start-up, technology R&D, employees—and with family and friends of all of these being targeted. Patient group partnerships (Parkinson’s) and specific groups (pregnant women) have also been targeted. 23andMe (2011) announced in an article on their blog called ‘The state of the database address’ that they had scanned 100,000 genomes since launch. The average age of participants is 45, and of these 57% are male and 47% are sharing their genomic information with others.

Announcements about the growing use of the services, as well as celebrity endorsement, may enhance perceptions that collectivity is being realised. Collectivity, and thus political agency, is specifically foregrounded by 23andMe through the ‘sharing’ and ‘community’ facilities, including a currently offered feature called the ‘relative finder’. These facilities enable users to make their scans available to other users and this mode parallels the social operations of Facebook. The bulletin-board style discussion area within the site frames participation in discussion about the scans as a community activity. This is in addition to the external blog (*The Spittoon*), which provides science news and offers a more extensive sense of being in a media network.

23andMe also has a research directive called *23andWe*, which is presented as a ‘new paradigm for genetic research’ (*23andMe.com*). This offers customers the opportunity to participate in research about disease association. In addition to sending in their saliva samples for genotyping, those who engage with this service participate in surveys to build-up phenotypic information. There has been debate about the value of this kind of user-generated information for genomic research. Nevertheless, *23andMe* claims that 76% of participants are involved in research with them (*23andMe, 2011*) and has published scientific findings based on their customer data in the US-based public library of science journal *PLoS Genetics* (Eriksson *et al.*, 2010). This enhances the imaginary of an active and sharing *23andMe* public with the capacity to change the power relations of biomedicine because it casts participation as part of an open-source public science initiative. The publication of this paper marked a step in establishing the credibility of genomic research deriving from DTC genomic services. The paper quickly came under critical scrutiny, including that of the Stanford University Center for Biomedical Ethics which condemned it as involving ‘commercial exploitation’ (Tobin *et al.*, 2010). Whilst *23andMe* has celebrated their placement of consumer-publics at the centre of genomic research, others have condemned this category convergence as the following evaluation from the Stanford Center suggests: ‘we believe this study presents significant ethical problems, problems that might be repeated in future research involving people who fall into the complicated category of customers/research participants’ (Tobin *et al.*, 2010, unpaginated).

In this mixing of the categories of customer and research participant there is also the making of a public at the interface of media audiences and biomedical research. This occurs through an address to citizen-consumers of genomics, who become informed and consenting research subjects for genomic science, and economic investors in digital information architecture, biotechnology and drug development. It involves an engagement with several different kinds of actors: the genome scanning company, those taking up these services, their genomes, genomic researchers and media audiences. Take-up of this address can include a range of activities, from just logging on, to sharing personal genomic information with others, joining online discussion, and/or interacting with a large and so far continually growing database of literature on association studies. Participation may also extend to sharing genomic information with others within *23andMe*, blogging, following *23andMe* on *Twitter*, disseminating genomic information within *23andMe* and outside, via other web media such as *SNPedia*. Although the number of people directly involved is limited, the circulation of publicity, talk, media coverage and meta-commentary on these practices is more extended. So, the imagined public at the interface of media audiences and biomedical research subjects has a much broader reach. The actors involved in *23andMe* and the media texts they co-produce, or complete, also intersect with the media coverage of this company and DTC as a whole.

Digital media can bring diverse forms together. The textuality of the digital interface brings a public into being by instantiating biotechnological ‘intimate–stranger relations’ (Warner, 2002, p. 57). This happens because genomics connects to some of the most intimate aspects of subjectivity—bodily dispositions—and reshapes them ‘around co-membership with indefinite persons’ (Warner, 2002, p. 57). *23andMe* consumers participate in an intimate networked public whose attention is orientated towards human genomics. This can take a variety of forms, ranging from giving ‘mere attention’, on the one hand, through to reading a blog entry, noticing the logo, etc., to critically comparing *23andMe*’s genotyping with those available from other testing companies, and open-source technologies. This public is not only a biosocial group (Rabinow, 1992; Hacking, 2006), it also constitutes a reading public orientated toward deciphering and annotating genomic information (their own and others) through digital media.

Performing the Biodigital Public

The tension at the heart of a consumer public is that it is both compliant and active and this combination is a feature of the dominant digital culture. Constituting an assembly of research subjects is crucial to *23andMe* and to DTC genomic services more generally. However, these assemblages are also productive in and through the circulation of media texts. The location of DTC genomic services in the context of digital media has been generative of a lot of talk, media coverage and commentary. Examples from the USA include high-profile articles such as ‘My Genome, My Self’, Steven Pinker’s (2009) *New York Times* piece, and Thomas Goetz’s (2011) ‘Welcome to the Age of Genomics’, in *Wired*. UK press coverage has included articles in the *Sunday Times* and the *Independent* by Virginia Ironside (2007) and Nic Flemming (2011), respectively. Flemming casts himself as a detective investigating different services, whilst the others look to the meaning of the genomic information for identity and health. [For further analysis of this coverage see O’Riordan (2012).]

One of the ways in which a public is made political is through the visibility of people to each other and to indefinite others. The press opens up genome testing to indefinite others in part. However, a more localised method for rendering customers visible to each other is through the operations of the bulletin board, which makes up the ‘community’ section of *23andMe*. This area is made up of approximately 270 pages of messages, some of these dating back to 2008. Each page lists 10 topics of discussion and each of these displays anything up to 341 responses, although most topics elicit a more modest dozen or so replies. This kind of bulletin board, along with email, is one of the internet’s most enduring conversation forms. These structures have facilitated computer-mediated conversations since the 1980s and they start with the posting of an initial topic and continue with a list of dated and timed responses, arranged chronologically, each containing the

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user names, and in total forming a ‘thread’. Threads underpinned the news groups of *usenet*, an early, but extremely popular, form of computer-mediated communication that preceded the web by at least a decade. A form of the bulletin board also reappears in the very contemporary *Facebook* ‘wall’ feature. The *23andMe* bulletin board provides a visible architecture for group participation in genome reading online, supporting, recording and archiving online conversations. They can be moderated, but they are open to an indefinite range of contributors or readers.

A crucial dimension of a political public is the ability of people to see themselves in and as groups. Hence, visibility is a crucial dimension of a public (Warner, 2002). This visibility can be imagined, metaphorical and metonymic, but as Warren Sack observes in his discussion of ‘Picturing the public’ (2008), it also needs to be supported by infrastructure. Similarly, Warner cites the infrastructures of print publishing as crucial in creating the conditions of possibility for address, response and visibility to both intimate and stranger audiences which are required in the making of a public (Warner, 2002). Likewise, by rendering the activities of consumer genome scanning and discussions about it open to view, the bulletin board section of *23andMe* realises the conditions required for the formation of a public.

In the case of *23andMe* there are several infrastructures of public-ness, but the performative operation of the ‘community’ part of the site is one of its most important features. The collective postings of those using the site are important means through which community is promised. There are large numbers of these postings, on a variety of topics, with many (sometimes hundreds of) responses. They demonstrate responses including enthusiasm and critical perspectives, and they constitute forms of conversation about genomic information and *23andMe*. The conversations are addressed to other users and to staff at *23andMe*. Generally users are visible to each other as comprising a collective of critical and engaged participants. Of course, the deletion of posts by a ‘community manager’ places constraints on these conversations and there are conventions about expression in this form. There is editing work undertaken by moderators which determines what is off topic, and this is particularly evident and appears to have the highest incidence in threads on the genomics of sexuality, or in references to sexuality in other posts.

Strategies for accentuating signs of participation and offering the promise of live and immediate communication include listing ‘most popular posts’, ‘most popular tags’ and ‘top monthly contributors’. Next to each page view of a community post there are also six thumbnail images of ‘recently active’ people. These help to give a face to the community. Clicking on the thumbnail image takes the reader to a user profile. The time-based record of postings (e.g. ‘2 hours ago’), also contributes to a feeling of immediacy and to the possibility of real-time interactions, as well as suggesting the possibility of contiguous discussion over time. Community posts are organised into affinity groups by *23andMe*, currently under the titles ‘Health’, ‘Maternal Line’, ‘Paternal Line’, ‘Relative

Finder’, ‘Product’. Within these groups the community posts are often about making connections: ‘does anyone else have’ or ‘share please’ are dominant imperatives.¹

Those who participate in *23andMe* instantiate a homogenous conversation insofar as they demonstrate compliance with conventions about digital etiquette and rules of conversation about genomics. In this sense, they can be thought of as operating in relation to a kind of learned behaviour or technoscientific habitus about both digital culture and genomics. Melissa Gregg has worked on the intersections of social media and work and points to the class dimensions of the white-collar work cultures of *Facebook* (Gregg, 2010). She uses the theory of the sociologist Pierre Bourdieu (together with that of Erving Goffman) to argue that *Facebook* modes of connection encourage groupings around specific tastes and class homogeneity:

The homophilic tendencies these platforms favor certainly make them significantly implicated in extending the present digital divide (Gregg, 2012, p. 100).

Gregg argues that social media exacerbate social tendencies towards grouping around similarities. As is clear in this quote, she also links this micro-level grouping around affinity or sameness to more structural inequalities.

The homophilic tendencies—or sameness—of digital consumer genomics are even more marked than those associated with more generic social networking sites of digital culture. Genome-wide association studies (GWAS) are based on association forms of homophilic grouping. These underpin the genomic information proffered against the genome scans in the reports provided by *23andMe*. In other words, the genomic information in both the raw data and reports generated by scanning emphasise genetic similarity and biosocial grouping. Association studies are crucial to human genomics even in its emergent incarnation as personal genomics and genomic information is relevant only to those associated populations. Even as it is personalised, genomics provides grounds for connection through its core perception that all humans have genomes and the expectation that, therefore, genome reading has an indefinite reach. However, as will be discussed below, the cultures of genome scanning and sequencing are orientated towards technological and media elites who constitute the main participants.

In addition to exhorting people to share information and to emphasise genomic association, *23andMe* also has an explicit vision of technoscientific subjectivity. The call to customers to become consenting research subjects who may participate in the genomic ‘research revolution’ comprises an invitation to be in the technoscientific know. The invitation to participate is framed in terms of improving future healthcare, although the site materials consistently disavow the medical use-value of the scanning service.² Thus, customers of *23andMe* are called upon to become the willing research subjects of human genomics. The *23andMe* blog (‘The

Spittoon: more than you've come to expectorate') reinforces this subjective invitation by offering an accompanying scientific news report. This extends the public media circulation of these activities, in a form comparable to a magazine with its readers. Reports on research from leading scientific journals are displayed through *The Spittoon* as are regular features such as the *SNP watch* report on the latest genome-wide association studies. This reporting is a form of popular science writing: it aims to be accessible and is often presented in a humorous manner. The following headline from a blog post illustrates the characteristic style of such postings:

SNPwatch: the bad driving gene? New research suggests that your skills behind the wheel may be affected by your genes (*The Spittoon*, 30 October 2009).

This emulates the 'gene for x' stories of the 1990s and provides evidence of ongoing geneticisation in the twenty-first century. However, this item is part of a set of in-the-know jokes about geneticisation in a mode that might be characterised as post-geneticisation. The text plays with the tropes of geneticisation and reporting styles of a prior genre. It does this through its humorous tone and by conveying some scepticism about genomics, even though *23andMe* is simultaneously fixated on it.

In line with this popular science mode of address, those who participate in the community sections of *23andMe* engage through technoscientific affiliation. Participation in the community area requires that they demonstrate their possession of both technocultural and economic capital. Familiarity with genomics, as well as with modes of online communication, together with the confidence to post about genomics in a public forum, is required of participants in the community section. The communication architecture, as well as the content of the section, foreground and reinforce the privileges of those with technocultural capital—a male-dominated technological elite. There is something of a contradiction between the address of *23andMe*, which is very accessible and generally user friendly with clear illustrations and non-technical language, and the take-up in the community forums which are dominated by an inaccessible and highly technical language.

In their 'State of the Database' article, *23andMe* announced that there were 100,000 posts in the forums. This extends to hundreds of pages and covers a range of topics. An extremely popular thread on the genomics of blood type clearly illustrates the way this talk enforces and reinforces technocultural elitism. In this thread the main discussion was about how to determine ABO blood type from raw genome scan data. There was a full and very detailed discussion of why blood type and genomic information do not correspond in predictable ways. Many of the posts included sections of raw data for comparisons, the types of gene chips used for testing also came into the discussion, and a variety of

genomic science references peppered the conversation. This content revolved around the display of expert and specialist knowledge about genome sequence reading and meaning-making. This language is reminiscent of technology orientated discussion forums around programming, coding and digital media production. Whilst women do participate in these fora, they are male-dominated. It is notable in this context that the only comment in the 130 replies on blood typing which resisted a mode of competitive technical expertise was by a female-identified poster who commented that, although useful, most of it was ‘over her head’.

The configuration of *23andMe* is unusual for a biotech start-up in that the founders of the company were women and there has been involvement from women at a high level within it. Nevertheless, the form and content of the online discussion in the site is gendered in its technological discourse. This highlights some of the limitations of the public of genome sequence reading more generally. The modes of operation are often elitist and gendered. They do not evoke a radical politics but, instead, they reinforce conservative aspects of public dynamics. The threads in the *23andMe* community are similar to *usenet* not just in form, but in their content of exclusive, male-dominated technical speech. Thus, although new public formations may be generated through the circulation of genomes as digital artefacts, *23andMe* does not generate a forum for a new kind of politics.

Spitting as Social Networking

23andMe adds genomic information to the 2.0 brand and the digital mix. Through the bio in this form of digital, those who engage are offered the possibility of new forms of authorship of and identification with internet texts which circulate to an indefinite audience. Warner (2002) argues that, for a public to be in formation, people must be able to: identify with the media texts that circulate; be able to contribute to them; and also have opportunities for antagonism and indifference. He also contends that abstract connection is not enough for a political public, but that corporeal investment or a sense of bodily participation could be thought of as a condition of politics. Genome scanning involves corporeal investment and potential identification, not least because the participants contribute bits of themselves which are attached to the circulating texts. This implicates them in the generation of the address. DNA is derived from the personal samples and genome scans are derived from this. The information returned is about aspects of embodiment. Consumers generate further content through sharing their information, commenting on discussion forums, engaging in questionnaires and quizzes, blogging or writing accounts of their experiences—all of which are activities which digitally inscribe their presence. These activities are performative in the sense that those involved provide evidence of their participation by generating content. In other words, this public is constituted by digital inscription. In a manner similar to that delineated by Warner (2002), this inscription into the matter of the public speaks

simultaneously to an intimate grouping involving biosocial connections (other genome readers) and to an indefinite and unpredictable audience of strangers.

725 *23andMe* ostensibly extends the 2.0 brand through the constitution of new kinds of databases which add a biological dimension to social networking. It structures a database ‘architecture of participation’ (O’Reilly, 2005) for human genomics, which celebrates and extends participation, whilst rendering user information (data) into commodities that can be used in biomedical research. Celebratory and utopian tropes of community and affinity predominate on the company interface. 730 At the same time, fragmented and specialised publics that can be subdivided by disease or genes are envisaged. The invitation to ‘share’ and to constitute groups, is offered through such a range of possible modes that Ian Hacking’s comment, ‘There are more biosocial groups on earth Horatio, than are dreamed of in your philosophy’ seems appropriate (Hacking, 2006, p. 94).³ The following excerpt from the 735 site is representative of *23andMe* communications about collective research:

740 *23andMe* is launching the Research Revolution to empower more people to jumpstart genetic research into the diseases that affect them and the people they love. This new research model makes it possible for large groups of people to assemble themselves into large-scale genetic studies without having to raise millions of dollars in funding, and then wait years for things to get rolling (*23andMe.com*, unpaginated web site, accessed 18 June 2010).

745 The invitation in this passage for ‘large groups of people to assemble themselves into large-scale genetic studies’ invokes an imaginary of public assembly. The language of revolution likewise promises political possibility. However, the invitation to become empowered also demands compliance, rather than revolt. 750 The invocation of self-assembly here holds out the promise of participants engaging in, and helping to develop, genomic research. These contradictions highlight the ideological dimensions of the discourse of interactivity, which obscures its own demands for compliance. In fact, the form of the participants’ action is proscribed here and the disciplinary aspect of the interactivity becomes apparent 755 because the outcome of the assembly is predetermined. Hence, in this case, the architecture for participation is also one for compliance. Whilst assembly is a key feature of a public, the invitation to assemble into a proscribed form (large-scale genetic studies) limits the capacity for political assembly. The language of 760 ‘jump-start’ and ‘revolution’ identifies genomic research as the site of a potentially valuable activity, realised through this exchange. The participatory modality channels the activity of consumers for the potential benefit of *23andMe* researchers and biotechnology partners interested in drug development, and invites participants to contribute to databases.

765 Through the use of ‘the spit kit’, members of the digital public of *23andMe* corporeally contribute to the company’s operations. Moreover, this practice, like

many others which produce and augment digital content, requires significant levels of participation for it to make any sense. This digital self-inscription operates performatively and recursively as it is the consumer genomes which make the interface appear rich in content and population. This practice also intensifies the promise of genomic information, identifying it as valuable to biotechnology communities. The value projected for the individual customer is promissory, construed through a nebulous framing with reference to ‘leverage’ and return:

(It) gives customers the opportunity to leverage their data by contributing it to studies of genetics. With enough data, we believe *23andWe* can produce revolutionary findings that will benefit us all (*23andMe*, accessed 18 June 2010).

The gesture towards ‘revolutionary findings that will benefit us all’ constructs an indefinite public in the address and blurs the distinction between consumer and investor. Such framing misrepresents the pattern of provision in the contemporary pharmaceutical industry, since such developments are unlikely to benefit ‘us all’. The status accrued through being involved in a high-tech start-up and the competencies afforded by genome sequence reading are likely to benefit primarily those who are already part of the biotechnological elite. This renders the reference to ‘us all’—indicating an expansive humanity—spurious, obscuring this company’s entanglement with structures that exacerbate digital divides and global inequality. The message that revolutions will occur in healthcare because of new studies in genetic research is one that has been repeatedly made and there has been a failure to deliver on such promise (Nightingale and Martin, 2004). This dimension of *23andMe* makes it compelling to suggest that the focus on biomedical issues in debates about DTC is misplaced. The biomedical reach of DTC is promissory and it is more instructive to look at what its practices are in the present, rather than to decide that they are biomedical.

However, *23andMe*’s appeal to ‘us all’ has another function. It works to construct a biopolitical public or a public deriving from the collective dimensions of genomics as a form of digital textuality. At the same time that the capacity for political participation in healthcare is limited through the ideological operations of personalisation and interactivity, there is an appeal to a genome sequence reading public. *23andMe* can’t itself deliver a revolution in healthcare because the political capacities of its public are so limited. However, as a constituent element in the circulation of texts, and as a generative agent within a broader media ecology, an unpredictable assembly of audiences is possible.

Personal Genomics: Putting the Bio into the Digital Public

The tensions between empowerment and constraint are evident in the following quote from the company in which the promise of empowerment is tied to that of intimate and stranger relations at once (Warner, 2002):

So when you send in that spit sample, you're not only learning about yourself, you're joining a community of motivated individuals who can collectively impact research and basic human understanding. In today's connected information age, it's no longer just about me. Instead, it's about how we can change our understanding of ourselves by joining together (*23andMe.com*, unpaginated website).

Compliance with the company is linked to a utopian vision of collective knowledge production with benefits for biomedicine and for humanity generally. However, assessing *23andMe* is not a matter of appraising the benefits or limitations of the forms of interactivity or personalisation associated with its service. Instead, I propose that this company and its offerings be conceptualised as embodying new modes of public assembly. In his study of another site of technoscientific provision (the contemporary science museum), Andrew Barry argues that 'putting the interactive model into practice promises to turn the unfocused visitor-consumer into the interested, engaged and informed technological citizen. Interactivity is more than a particular technological form' (Barry, 2001, p. 129). Like visitors to science museums, the consumers who participate in the digital genomics of the early twenty-first century are invited to become not just consumers, but also highly invested technological citizens. *23andMe*'s communal address is to an engaged citizen-consumer of science who is both an individual and part of a group, personal and public, a 'me' connected to a definite 'we'.

DTC genomics, in the form of *23andMe*, generates a biodigital public in three ways. Firstly, through changing saliva samples into internet circulated texts, embedded in genome browsers; secondly, through inviting participation in a public imaginary of genome browsing, producing and reading; and thirdly, through the generation of media cultures of genomics. Considering these three layers of public-ness—personal, corporeal investment in the circulation of texts; awareness of a collective horizon of public-ness; and intersection with an indefinite horizon of media publicity—together offers a way of thinking about how publics are formed around consumer engagements with genomics.

Genomes are currently being examined for information about a range of issues, including: ancestry, race, behaviour, sexuality, ear-wax consistency, the colour and smell of urine, the capacity to metabolise coffee and the probability of getting Alzheimer's disease. The diversity and unevenness in value and significance of these genomic investigations is bewildering. However, expectations for genomics are by no means restricted to the goals suggested by the foregoing list of issues under investigation. Indeed, speculation about the prospects for future identification of genomic associations has been almost limitless. Like stem cells, genomes have become pluripotent signifiers, through the hyperbolic rhetoric around them, the overwhelming amount of information generated and uneven understandings of developments in this field. *23andMe* capitalises on these features of contemporary genomic technoscience by remaining vague

about what their product is useful for, whilst cultivating a generalised sense of its promise of empowerment. This excess of signification puts this company beyond the reach of regulatory frameworks that rely on bounded categories such as medical/non-medical. It also means that the kinds of texts generated through *23andMe* are unpredictable in their capacity to signify.

Theories of media and technological convergence often point to the computer as the nexus or point of intersection for all other media. Some media theorists have argued that this transforms the contemporary social world into a digital culture. Mark Poster (1990) framed this as the mode of information, and this has also been characterised as a networked society (Castells, 2000), or as instantiating posthumanism (Hayles, 1999). This culture is deemed to be distinct from the modern print culture which preceded it. At the consumer interface with digital genomics, what seems to matter is not so much everything going through the computer. Rather, it seems that everything appears to come together in the bioinformatic genome. In this sense, the genome also becomes a point of convergence (Thacker, 2004) in a context in which the metaphor of code-script frames understandings of DNA, genes and genomes (Hayles, 1999; Kay, 2000; Roof, 2007). This is further instantiated by the recent bioinformatic framing of genomes as things that operate through browsers (Cline and Kent, 2009). Although it is important, this general framing of genomics as informatic can obscure other features of this biotechnological field. It gestures towards the ontology of the genome as digital, but it does not highlight how genomics is taken-up and circulates.

Contemporary digital publics operate through interactive, networked modes and theorist Danah Boyd argues that there is thus a kind of being 'public by default' (Boyd, 2010). Seen from this public-as-default perspective, privacy is constituted by going offline. However, it is not always possible to withdraw from digital media once inscribed therein. For example, to participate in *23andMe* requires informed consent signified by payment, by ticking the 'I have read' section on the consent form, by certifying the user's age as over 18, and by responding to surveys that elicit further 'I have read' disclaimers. *23andMe*, on the one hand, undertakes to destroy DNA samples after scanning and offers their customers the possibility of withdrawing their genomic information. Nevertheless, their lab does keep the scan data on file (anonymously) and withdrawals of samples are only permitted if *23andMe* have not already shared the genomic data with a partner or processed it as research.⁴ In this context, informed consent is only partially in operation. Once a genome scan is circulated as a text it is also recorded in a lab, embedded in a browser, annotated for research, released as raw data, and linked to surveys in *23andMe*'s research. There is no real possibility to retract a contribution to such a dispersed presence.

Digital media systems are constructions in which individuals are both compelled and enabled to interact and this has both open and compliant dimensions. The take-up of *23andMe* does not work predictably in relation to the company's conventions and prescriptions. Hence, within the digital scene of circulation,

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evaluations and critiques of *23andMe* emerge and critical assessments of the value of genomic information are registered alongside its valorisation. Consumer engagement with *23andMe* makes genomics a lively field for research and it also enables the emergence of critical relationships with genomics.

Conclusion: The Interactive Personal–Public: A Biodigital Mode of Attention

I return here to the question posed in the introduction: what are the political dimensions of digital genome reading? The generation of personal genome scans and sequences and their circulation enables the production of a new digital genomic public. This public is a hybrid entity created in the coming-together of audiences and consumers through an address. The incorporation of a public is realised through audience attention to genomics, consumer co-creation of genomic information, and the publicising of human genomics through and around these practices. This is a homogenous and compliant public. The features of DTC genomics are contradictory but indicate the conditions of a contemporary collectivity that is at once embodied and informatic, empowered and coerced, personal and public.

The public addressed by *23andMe* is both thoroughly embodied and thoroughly mediated. Bodily materials are made into informatic forms and rematerialised through these digital media. Referring to very similar processes to those by which materials such as saliva and the DNA of individuals are repackaged as personal genomic information, Eugene Thacker (2004) has coined the term ‘biomedial’. This connects to the idea of a biodigital public because participation in *23andMe* delivers genomic texts that are both informatic and bodily, into a public mode of circulation through digital media.

Discourses of personalisation and of interactivity are generally associated with empowerment in their respective spheres of health and digital culture. These discourses and their denotation of empowerment figure strongly in expectations for genomics. Nevertheless, as I have demonstrated, despite its associations with both personalisation and interactivity, genomics is by no means straight-forwardly a vehicle for empowerment. Indeed, it is precisely the tension between the promise of empowerment and its denial which has been highlighted in the foregoing examination of digital genomics through a case study of the DTC genomic provision offered by *23andMe*.

This constitution of a biodigital public instantiates a disciplinary force with its own forms of docility which are obscured through the promises of democracy, revolution and empowerment cultivated around it. Following Barry’s understanding of interactivity as ideological, we can see that social media’s promise of empowerment obscures the inequalities that digital culture and genome reading exacerbate. Extrapolating from his research (Barry, 2001) it is possible to trace

how the promise of interactivity obscures the shift into compliance involved in giving up genomic information.

However, this formation also offers opportunities for public intervention by making genomics more open to view. Furthermore, the emergence of celebrity genome scanning as media content intensifies the sense of promise associated with these developments. If the method of engagement of *23andMe* (and other similar DTC genomic scan providers) is to make its participants practitioners and authors of their own circulating texts, this may also elicit critical readers with a stake, not just in the texts, but in the modes of circulation. In other words ‘welcome to you’ is a highly effective strategy for focusing reading attention on a point of identification in the text. Hence, and rather ironically, making genomes increasingly personal also makes them more public.

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Notes

¹It is worth noting that there is an extensive literature on computer-mediated communities in which the nature and possibility of community is debated, which will not be reviewed here. See, for example: Jones (1994) and Baym (2000) for informative discussions about the nature of online communities, and Sack (2008) and Gregg (2012) for very different takes on some of these debates.

²This is referred to as a contract in bad faith by Andrew Yates (2010) blogging on *Think Gene*. He argues that *23andMe* appears to be disclaiming the medical use value of their genome scans in order to avoid regulation, whilst encouraging its customers to provide testimony as to how they have used scan information for healthcare.

³Certainly there are more biosocial groups than Ian Hacking imagined when he wrote this in 2006. In a discussion at ‘On the Human’ (Hacking, 2009) he acknowledged that he had not considered the formation of ‘previvor’ groups. This term refers to individuals who identify around their diagnoses with genetic pre-dispositions to particular conditions but who have taken strategies to survive. The term has recently been used to designate women who have been diagnosed with predispositions to breast and ovarian cancer, and who have undergone double mastectomies and/or oophorectomies as strategies to pre-empt cancer.

⁴*23andMe* partners include Illumina (a gene chip development company), the National Parkinson Foundation (a US patient group) and Palomar Pomerado Health (a US healthcare provider).

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